EMERGING ADULTHOOD CAREGIVERS:

EXAMINING THE UNIQUE EXPERIENCES IN THIS

UNDERSTUDIED POPULATION

By

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EXPLORING EMERGING ADULTHOOD CAREGIVERS: DOES THIS UNDERSTUDIED POPULATION VARY FROM MIDDLE AND LATE ADULTHOOD CAREGIVERS?

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Abstract: The majority of caregiving literature either focuses on child and teenage caregivers (Shifren, 2009) or middle and late adulthood caregivers (Blum & Sherman, 2010; Bastawrous, 2013). Because of the skewed focus, emerging adulthood caregivers are poorly represented in research and practice. Categorizing caregivers as either young or adult caregiver aids policymakers to develop general services; however the caregiving categories encompass two or more developmental periods. Assuming a caregiving role at an unexpected time during the life course can interfere with the psychosocial tasks of a given life stage; creating a disruption and causing the caregiver to feel "off-time." The purpose of this study was to explore the characteristics of emerging adulthood caregivers to determine how the caregiving role impacts this population. The sample for this study (n=118) was a convenient sample of students recruited from large undergraduate university courses. The Caregiver Well-being Scale-Short Form, Zarit Burden Interview, Positive and Negative Affect Schedule, and the Life Experiences Survey, as well as two original scales were used to assess constructs of caregiving activity, caregiver well-being, psychological affect, health literacy, caregiver burden, and transitions. Results show that unemployed, single, white females are more likely to provide care. Quantity of transitions was not found to influence psychological affect or caregiver burden. Caregiving activity was correlated with caregiver burden such that higher levels of burden were correlated with higher levels of burden. However, caregiving activity was not correlated with well-being or psychological affect. Emerging adulthood caregivers typically do not perform the primary caregiving role, yet the individuals occupying the secondary and tertiary roles can still experience strain or overload. Even though caregiving was defined for them at the beginning of the study, emerging adults either reported that they did not identify themselves as a caregiver due to familial obligations or incorporated their own views and past experiences into the definition of a caregiver. Further research is needed to focus on primary emerging adulthood caregivers to determine the risks and benefits of this population. By understanding the emerging adulthood caregiving population, more beneficial services can be developed to aid this population.

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INTRODUCTION

According to the 2010 census, 13.7% of the US population is over the age of 65 (U.S. Census Bureau [USCB], 2012) and is estimated to reach 20% by 2030 (Clawson & Ganong, 2002; Silver & Wellman, 2002). The increasing longevity of older adults is correlated with the prevalence of disability and functional dependency, increasing the need for a primary caregiver. As of 2008, 65.7 million informal caregivers made up 29% of the US population (Family Caregiver Alliance [FCA], 2012), an increase from 44.4 million in 2004 (National Alliance for Caregiving [NCA] & AARP, 2004). In order to understand and aid this growing population, researchers have focused their resources on the physical, psychological, and emotional needs of family caregivers.

An informal caregiver, also represented in the literature as a family caregiver, is "anyone who provides unpaid care and support to an adult friend or family member who is disabled, chronically ill, frail, or elderly" (O'Connor, 2007, p. 165). While many agree on the caregiver concept, the term is subjective in nature and hard to define. Further complicating the issue, caregivers may not identify themselves as such because they perceive their tasks as 'what families do for each other', demonstrating a value of filial responsibility. Finally, caregivers enter into their roles in various ways and under various

circumstances. Some gradually work into their roles while others become full-time caregivers overnight. While the circumstances of caregiving vary from family to family, there is a significant need to better understand the developmental trajectories of caregivers of all ages and stages. The aim of this study was to: 1) explore characteristics of emerging adulthood caregivers; 2) determine to what extent life transitions and trajectories influence psychological affect and burden in caregivers; and 3) determine if emerging adulthood caregivers merit consideration as a distinct group in the classification of family caregivers.

Definition of Terms

To better understand the context of this study, it is key to understand the meanings of several key terms. The definitions of these terms are as follows:

Informal caregiver: an individual who provides any type of physical and/or emotional care for a family member or a friend, without compensation (salaried position/hourly wage).

Care recipient: the individual who receives care from the informal caregiver.

Primary caregiver: informal caregiver who takes primary responsibility for a family member or close friend; recognized by the care system as the point person, this individual makes all or most decisions (Day, n.d.). There is only one primary caregiver.

Secondary/Part-time caregiver: informal caregiver who provides some care for the care recipient in support of the primary caregiver, may also step in to provide a temporary period of relief for the primary caregiver (Day, n.d.).

Intermittent/Tertiary caregiver: informal caregiver who provides minimal or passive care to the care recipient; also may provide support from afar (Day, n.d.).

Transitions: a major event that changes a person's status or circumstances (Newman & Newman, 2007).

Activities of daily living (ADLs): essential activities of daily self-care, such as feeding, bathing, dressing, grooming, and leisure.

Instrumental activities of daily living (IADLs): important but not necessarily daily activities that are central to individual functioning, but allows for independent living in a community. Activities include taking medications, balancing finances, shopping, telephone usage, and transportation.

Health literacy: the degree to which individuals have the capacity to obtain, process and understand basic health information needed to make appropriate health decisions and receive services needed to prevent or treat illness (Ickes & Cottrell, 2010).

Well-being: self-reported evaluation of an individual's satisfactory condition of existence: in this study, physical, psychosocial, and financial.

Psychological affect: the experience of feeling or emotion related to caregiving involvement; in this study, the positive and negative emotions involved in caregiving.

Burden: the negative reaction to the impact of providing care on a caregiver's social, occupational, and personal roles.

CHAPTER II

LITERATURE REVIEW

Brief History of Caregiving

Families have been providing informal care for loved ones across time; however it is only within the past several decades that it has become a major social issue. Between 1900 and 1998, demographers have seen a steady increase in life expectancy from around 50 years of age (Kinsella, 1992) to 78.7 years of age (Murphy, Xu, & Kochanek, 2013). As the population has grown older, incidence rates of degenerative diseases have increased as well. In 1965, Congress passed the Older Americans Act (OAA) to provide services for the growing aging population (Gelfand, 2006). The overall goal of this act is to aid those 60 years or older, by allocating funds for research, programs, and trainings to each state. Through the OAA, the Area Agencies on Aging were developed to help identify older individuals who require services and help connect those individuals to those services. These programs include but are not limited to supportive services such as transportation, residential repairs, nutritional programs, as well as senior centers.

Numerous older adults have benefitted from the OAA services, but as individuals outlived their retirement funds and social security allowances, new options had to be found. Chronic conditions (e.g., Dementia, cardiovascular problems, etc.) impose on the freedoms of older individuals by limiting their functional ability; requiring consistent

medical attention. In 2006, Social Security was paying seniors on average $1,002 a month (Gelfand, 2006), while live- in caregivers can cost from $700 to $3000 a week (Geewax, 2012). Something, or rather someone had to fill in that monetary gap: families providing care for older family members.

As the family caregiving population increased, researchers began to notice physical and mental issues that were being experienced by these individuals. The majority of caregiving literature either focuses on child and teenage caregivers (below the age of 18) or around the average adult caregiver, a 45-year-old woman. Because of this skewed focus, late adolescence and emerging adulthood are poorly represented in the literature. Gray, Robinson, and Seddon (2008) defined young caregivers as "being under the age of 18, whose lives are affected by the care needs of another person who may have disability or long term illness" (p. 169); denoting caregivers above the age of 18 as adult caregivers. On the surface, these two categories aid policymakers to develop general services to help caregiving individuals. However, from a developmental standpoint, each caregiving category contains two or more developmental periods (Erikson, 1963). Each developmental period contains stressors that vary from the preceding stage and the stage that follows. These ever-changing stressors create new interactions between the individual and societal pressures, creating distinct developmental periods (Newman & Newman, 2007). In an attempt to understand the growing population, these developmental periods were overlooked, thus little research has explored how caregivers differ across the lifespan. By understanding the minute differences in the various subgroups within the caregiving population, more beneficial services can be created and existing services tailored to reach a wider population.

Theoretical Framework

With the rising population of older adults, the number of informal caregivers has increased exponentially in order to provide care for the older population (NCA & AARP, 2004, 2009). These increases have left researchers and policymakers scrambling to develop services to care for these populations. However, individual differences between caregiving situations were overlooked in the haste to provide necessary services. Because of the importance of these variations in human development, a life course perspective will be taken to account for inter-individual differences. Life course theory seeks to understand the interactions of ever-changing societal norms and social forces that influence an individual's development (Newman & Newman, 2007).

Development is facilitated through the constant interaction of an individual and the individual's social environment (Newman & Newman, 2007). These interactions are viewed through two central concepts of life course theory: trajectories and transitions. According to Newman and Newman (2007), a trajectory is defined as the "long-term path of one's life experiences in a specific domain, particularly work and family life" (p. 189), while a transition is "a component within the trajectory marked beginning or close of an event or role relationship" (p. 189). In other words, a trajectory is the path that an individual views taking in a specific area of life, such as work. A trajectory for an individual's career could be starting at the bottom of the company, then earnings a promotion, then another promotion, and so on until the person has reached as high as possible in the company. A transition, within this scenario, would be obtaining that first job or being promoted to a new position. Trajectories are composed of transitions and life course theory uses these concepts to explore the impact of societal change on individual

lives through observing the changes in these transitions and trajectories (Newman & Newman, 2007).

Four Principles of Life Course Theory

Human development takes place in historical time and place. An individual is a function of society, influenced by the societal conditions and historical contexts of that time period (Newman & Newman, 2007). Someone born in 1920 would have a much different experience transitioning through marriage, parenthood, work, and retirement than someone who was born in 1950. Society is constantly changing with advances in medical technology, education and career opportunities, as well as influenced by the amount of people in a specific cohort (Newman & Newman, 2007). Major societal crises (e.g., war or political unrest) can also shape an individual's development by altering trajectories through unanticipated transitions (Newman & Newman, 2007).

Applied to the realm of caregiving, individuals who assume the responsibilities as a family caregiver have experienced events that have shaped their development and how their responsibilities are completed. As mentioned above, Newman and Newman (2007) state that major crises influence development through altering an individual's trajectory. Caregiving, which is emerging as a social crisis, alters an individual's trajectory by influencing the caregiver's decisions with various transitions. A caregiver may put off a big promotion at work, entering into an intimate relationship, or procreation because of time restrictions. This limitation further affects development by impacting future transitions and trajectories.

Researchers, however, cannot just focus on the caregiver's development. Caregiving is a dyadic relationship that involves the constant interaction of two

individuals. Care recipients are not static beings, but fluid individuals who have experienced numerous transitions already that have shaped their development. Caregivers must take into consideration the care recipient's historical time in order to understand the care recipient's attitudes and behaviors.

People act in their own best interest to opportunities available to them in their time and society. Along the life course, individuals are offered choices that help them build their life course that is different from another (Newman & Newman, 2007). Individuals choose to accept better paying careers or move to better living conditions, as well as many other decisions that increase their quality of life. However, by choosing to take on the responsibility of providing care, caregivers contradict this principle of life course theory due to the notion that this choice is not always in the best interest of the caregiver. Informal caregiving has been linked to poor mental and physical well-being (Blum & Sherman, 2010; Hoffman, Lee, & Mendez-Luck, 2012), increased levels of stress (Lisa, MacNeil, Mobily, Teague, & Butcher, 2012), and impacts multiple facets of an individual's life. These constructs will be discussed further below. To understand this contradiction, researchers have begun to explore the reasons that caregivers take on this overwhelming role. When asked, most caregivers reported that they felt obligated to help their family member, even if it was not in their own best interest.

The timing of lives, especially social time and societal meaning of age, provide structure to the life course. Social time focuses on when an individual begins or ends a social role, the progression of social roles, and the expectations of these roles (Newman & Newman, 2007). Social pressures prod individuals to partake a particular role at a specific time. Along with these pressures, age norms inhibit behavior that is

inappropriate for an individual's age (Newman & Newman, 2007). By using societal pressures and age norms as a guide, individuals are able to determine if their behavior is "on-time" according to the social clock. Caregivers, however, cannot set their behaviors by this clock. Illnesses may have a rapid onset or a traumatic incident, such as a stroke may occur, forcing the caregiver to assume responsibility before the socially appropriate time. Thus the caregiver may begin to feel "off-time."

Lives are linked through various social means. The first concept of this principle is that society links individual lives. If an aspect of society is straining an individual, then that individual may become tense and lash out at other individuals. This interaction may influence another individual's life course. An example would be a parent is laid off from work, causing marital discord due to redirected frustration at the spouse. This discourse then affects the child. For informal caregiving, the numerous responsibilities of providing care can create stress on the caregiver, increasing the individual's level of burden. The caregiver may begin to become frustrated more easily with the care recipient, creating an unsafe environment for the care recipient.

Emerging Adulthood

As mentioned above, life course theory analyzes development not as a stage independent of the social conditions of the time period. Erikson's psychosocial theory explored development as an interaction of biological, psychological, and sociological factors, but the era in which the individual developed was overlooked (Newman & Newman, 2007). One criticism of psychosocial theory is that Erikson discusses distinct stages for adolescence and young adulthood, but does not include a stage that can be considered congruent with emerging adulthood (18-25 year olds; Arnett, 2000). Erikson

believed that industrialized societies permitted an elongated adolescence (Arnett, 2000, 2004). Recently, emerging adulthood has evolved into a distinct life stage due to demographic changes; adapting to new societal condition and historical change. Emerging adults have postponed marriage and procreating until their late twenties (29 for males and 27 for females; USCB, 2014), leaving the late teens and early twenties exposed to a variety of life trajectories. Subjectively, individuals within this life stage do not classify themselves as adolescents nor entirely as adults (Arnett, 2000), leaving the individuals in an ambiguous state. In an attempt to discover who they are, emerging adults explore their identities. This finding conflicts with Erikson's view that identity exploration is the central crisis of adolescence. Because of this overlap, it is imperative that emerging adulthood be included when looking at caregiving populations. It is important to note that Erikson's work cannot be generalized to all individuals due to his focus on males.

Social Role Theory

"All the world's a stage" (Shakespeare, trans. 2004, 2.7.1037). Drawing from the realm of theater, social role theory is centered around how each member of society across the lifespan not only obtains positions and statuses, but also the expectations and behaviors that accompany each role (Newman & Newman, 2007). According to Social Role Theory, the numerous complex and diverse roles that an individual assumes facilitate socialization and personality development across the lifespan (Newman & Newman, 2007). A role is any set of behaviors and accepted norms that society has agreed upon for a specific function (Newman & Newman, 2007; O'Connor, 2007). Newman and Newman (2007) point out that when a role spans across many life stages,

such as a parent or caregiver, the specific norms and behaviors associated with this role become integrated into the individual's self-conception. Furthermore, new roles are accompanied by internalized expectations about the enactment of these roles, leading individuals to define themselves by the important roles they hold (Newman & Newman, 2007). By that notion, individuals who are providing informal care for someone should define themselves as a caregiver. However, several studies have found that many caregivers do not identify themselves or assume the role as a "caregiver"; these individuals just believe that it is an extension of their role as a spouse or child of the care recipient (O'Connor, 2007; Smyth, Cass, & Blaxland, 2011). Whether or not the individual has identified himself or herself as a caregiver, the responsibilities remain the same. Thus the role of a caregiver, by extension, is added to other roles that the individual portrays.

As stated above, each role is accompanied by socially expected behaviors to complete; some roles may have few behaviors and others may have many that must be enacted. Furthermore, occupying multiple roles increases the likelihood that some expected behaviors would overlap, forcing the individual to prioritize the various occupied roles (i.e., child's school function or preparing for an important meeting at work); defined as role conflict (Newman & Newman, 2007).

An emerging criticism of social role theory is that the roles an individual occupies are too static (O'Connor, 2007) and that the function of a role is to describe how individuals experience and enact societal relationships (Luberda, 2000). Scholars have found that society influences the average expectations of each role; however they are unsure to what degree these social pressures influence the individual in any specific role

(Luberda, 2000). To account for these social influences, social psychologists have proposed *positioning theory*. According to Luberda (2000), the term position inherently suggests flexibility, showing that individuals are ever changing. O'Connor (2007) stated that a position bestows a set of rights and duties that lend meaning to an individual's actions and allows insight into the developing personal identity. Roles and positions are similar concepts in that each provides direction and meaning to the type of action one engages in, but a position is constantly shifting with conversations and is constantly negotiated (O'Connor, 2007). In other words, position moves beyond the traditional thought of roles as pre-determined by society. O'Connor (2007) discusses that shifting the focus off the "role" to the "position," scholars look beyond the formal and static to a more dynamic and negotiable aspect of interpersonal and intergroup interactions. Positioning theory has begun to gain ground in the caregiving literature because of the subjective and personal nature of each caregiving dyad. The caregiver and care recipient must determine not only how to enact their own positions, but also how to interact with each other in an efficient manner for that specific dyad.

The caregiving role has become to be identified as a career, denoting a greater length of time an individual dedicates to this role; a new trajectory (Ducharme, Lévesque, Lachance, Kergoat, & Coulombe, 2011). By incorporating this new trajectory and the numerous transitions that are incorporated therein, the caregiver must be flexible enough in the individual's various occupied roles to compensate for deficits that may arise in other areas. Chronic illnesses can affect an individual, such as dementia affecting an individual's memory. Caregivers must be flexible in their positions as caregivers to adapt to the numerous pathways that an illness may take.

For this study, the roles in which an emerging adulthood caregiver possesses will be denoted by the quantity of life transitions. A life event (a transition) can add to the individual's social roles (e.g., marriage, beginning a new job, etc.). By taking this line of thought, the quantity of life events could indicate the quantity of social roles an individual has. If an individual has numerous social roles (indicated by the amount of transitions they have undertaken), then that individual could be experiencing overload and begin to feel burdened. With fewer social roles, the individual may be able to complete their tasks competently, thus have a lower experience of burden (Otis-Green & Juarez, 2012).

Caregiving Types

Beyond the distinction of young or adult, caregivers are further classified based on the amount of care that they provide: primary, secondary, or intermittent. According to Day (n.d.), primary caregivers provide full-time care for the care recipient, and most often are living with the care recipient. Furthermore, a secondary caregiver provides part-time care or occasional relief for the primary caregiver. A secondary caregiver may be an adult child who assists with cooking or cleaning for the care recipient or provides the primary caregiver with a respite for a short period of time. The third distinction, intermittent, further denoted as a tertiary caregiver. This third level caregiver is typically someone who provides care from a distance, whether by sending financial or provisional support. A tertiary caregiver also can be someone who may provide physical care, but on a very small scale, such as once a month.

Outside of primary care, it becomes more difficult to determine how secondary and tertiary caregivers are affected by caregiving responsibilities. These two caregiving

groups provide little to some care; however, it is unknown if providing care for a short period of time affects well-being or development. Secondary and tertiary caregivers are vital supporters for primary caregivers, yet there are not social services developed to serve this understudied population.

Developmental Disruption

Family caregivers do not usually slide into their caregiving role. Most commonly, this role is thrust upon them after a physical or mental disability has occurred (Pereira & Rebelo Botelho, 2011). They also may inherit the role from another individual after a tragic event occurs, such as a death. In either case, the onset of the caregiving role is sudden, leaving the caregiver scrambling to make sense of the situation. In an attempt to make sense of the situation, the new caregiver must come to terms with this new position and identity adaptation accordingly. Going beyond obtaining a new role as a caregiver, this individual must sculpt the other roles, or positions in life to accommodate the new position: caregiver.

No matter how a caregiver obtains this position, without proper preparations, caregivers may develop role ambiguity (Usita, Hall, & Davis, 2004). According to Silva-Smith (2007), role ambiguity relates to caregivers' feelings of having "inconsistent or incomplete expectations or directions concerning the role" (p. 100). This ambiguous feeling may create strain within the individual due to uncertainty of how to execute this new role. Pereira and Rebelo Botelho (2011) stated caregivers must learn how to integrate caregiving into their life trajectory, as well as understand the "process of making sense" (p. 2449) the numerous responsibilities that their new caregiving role entails.

In order to further understand the tolls the caregiving role exacts on adolescents and emerging adults, one must comprehend the normal developmental tasks during adolescence and emerging adults. Usita et al. (2004) proposed that assuming a caregiving role at an unexpected time during the life course can interfere with the psychosocial tasks of a given life stage. This disruption can create confusion about how to fulfill both the caregiving role and resolve the developmental tasks. This disruption may cause the caregiver to feel "off-time" developmentally with their peers. Abraham and Stein (2013) defined "off-timedness" as "difficulty attaining normative social roles or challenges maintaining current expectations" (i.e., executing current roles; p. 610). An important facet of caregiving is that adolescents and young adults who provide care for someone may see themselves in a developmentally, inappropriate adult role (Pakenham, Bursnall, Chiu, Cannon, & Okochi, 2006).

Adolescence. First and foremost, adolescents must grapple with developmental tasks centered on autonomy, connections with others, rebellion, and development of independent identity, and distinction and continuity with others (Bailey, 2006). Erikson conceptualized this developmental task as "identity vs. role diffusion" (Erikson, 1963); viewing this stage as an adolescent's struggle through identity development within the individual's own ego to gain a sense of sameness. Erikson also thought adolescents risked confronting role confusion due to sexual and vocational identity doubts (Bailey, 2006). The period of adolescence is a period full of experimentation in order to work out these doubts.

Accompanying these doubts are numerous developments: physically; emotionally and socially; cognitively; and morally. Physically, adolescents typically undergo puberty

during this stage and have an increased sexual drive. Peer groups are vital for social growth, but are unstable with membership fluctuations and ambiguous roles (Bailey, 2006). Bailey (2006) continues on by stating that it is through interaction with the environment that personality characteristics are shown to develop. This changing social environment appears to allow for adolescents to be exposed to a wide variety of social situations and social pressures. However, these environmental interactions must be intricately balanced with inherent determinants and unconscious processes (Bailey, 2006). Into later adolescence, adolescents begin to blend values from a variety of different sources into their own set of values. In order for this blending of values, adolescents must be able to think abstractly. Piaget theorized that adolescents begin the formal stage of cognitive thought, also known as the abstract thinking around the age of 11. This cognitive development is characterized by hypothetical deductive reasoning, metacognition, and abilities to grasp probabilities and think in abstract forms (Bailey, 2006). These abstract forms facilitate moral development. The ability to think abstractly, as well as internalized values, allows for the adolescent to derive more than one option to any given scenario (i.e., stages 3-4; Bailey, 2006), instead of the punishment and obedience orientation that is found in the morals of children (Helwig & Turiel, 2011).

However, under the shadow of caregiving, these developments can become disrupted. Caregivers spend a vast amount of their time juggling their responsibilities as a caregiver, as well as the duties of each role they possess. Adolescents require exposure to stimuli to stimulate thinking and allow for the contemplation of ideas (Siskowski, 2009). Furthermore, Siskowski (2009) points out that school provides these opportunities, but a national study found that one in five young caregivers report that their responsibilities has

caused them to miss school and after-school activities. Without this vital social interaction, the adolescent is unable to obtain the proper social growth or interact with the proper social environment to develop personality characteristics. When looking at self-worth, adolescent caregivers were found to have more feelings of worthlessness or inferiority to other children (Siskowski, 2009). These feelings have been shown to lead to an increase of antisocial behavior, which is correlated with an increased risk of bullying Salmivalli, Peets, & Hodges, 2011).

Late adolescents (15-18) begin to emotionally separate themselves from their families, establish adult relationships, and better grasp the gravity of the illness (Siskowski, 2009). Because of this, adolescents may put off dreams and aspirations to care for their family member. The adolescent, whose developmental task is developing an identity, may internalize the caregiving role and incorporate that role into their identity. The issue with this rationalization is that the caregiving role will not last the entirety of the lifespan. Losing the caregiving role and in essence a piece of their identity can create psychological distress while transitioning back to a life without providing care. Beach (1997) postulated that when an adolescent assumes the caregiving role, then the individual's identity development is delayed (as cited in Siskowski, 2009). This delay then allows for the adolescent to develop a new identity once the caregiving role has been given up. However, the limited exposure to social situations may hinder the values that the adolescents develop; further hindering the moral development of these adolescents.

Emerging adults. Carrying over from adolescence, (Arnett, 2000, 2004) states that emerging adults explore their identities further. This exploration is flamed by the emerging adults emancipation from their families (Dellmann-Jenkins & Blankemeyer,

2009). Becoming emancipated from their families allows emerging adults to make competent decisions, as well as develop a personal identity that becomes a launching point for development of intimate relationships; Erikson's fifth developmental stage (Dellmann-Jenkins & Blankemeyer, 2009; Erikson, 1963). One manner of emancipation is the entrance into a higher education institution, whether that is a two or four-year institution (Arnett, 2004). Emerging adults are taught new ideas and encouraged to complete their own research about topics to develop their own opinions, as well as sharing in collegiate fun through "friendships, camaraderie, romances, partying, and communal joie de vivre" (Arnett, 2004, p. 139-140). However, according to Dellmann-Jenkins and Blankemeyer (2009), young adults' sense of obligation to support their families increases significantly after graduation from high school. In 2001, Dellmann-Jenkins et al. found that more than one half of young filial caregivers were living with their older care recipient, instead of being emancipated from them (as cited in Dellmann-Jenkins & Blankemeyer, 2009). Positive outcomes were reported for these filial caregivers, but they were still found to be unemployed or underemployed. It is through successful emancipation from the family of origin that helps lay the foundation for the development of successful intimate relationships (Dellmann-Jenkins & Blankemeyer, 2009).

Social networks are generally at their all-time high during this stage, which help to boost self-esteem and decrease depressive affect (Dellmann-Jenkins & Blankemeyer, 2009). However, for emerging adult caregivers who do not have time to build social relationships outside of providing care, they may be unable to access these benefits. By extension, if someone were unable to socialize with friends, then dating another

individual would also be hindered. Dellmann-Jenkins and Blankemeyer (2009) noted that when emerging adult caregivers were asked about dating, many said that dating someone was impossible; interfering with the completion of Erikson's sixth developmental task of establishing an intimate relationship (Erikson, 1963). If the caregiving individual had established an intimate relationship, the relationship became strained because the caregiver did not make time for the partner (Dellmann-Jenkins & Blankemeyer, 2009).

Health Literacy

Individuals in these age groups do not normally assume the caregiving role, thus they may experience an uncomfortable feeling (Pakenham et al., 2006), especially since college students are relatively inexperienced as care providers (Baus, Dysart-Gale, & Haven, 2005). Adolescents and college students generally do not have adequate knowledge of age-associated illnesses. Kwok, Lam, Yip, and Ho (2011) completed a study looking at dementia related knowledge among health care and social professions and found that these students had poor knowledge about the disease and available treatments. This leads one to assume that if students who are studying age-associated illnesses have poor knowledge about them, then students who are not studying these illnesses would also have poor knowledge.

Continuing on the same path, most adolescents and college students do not have adequate knowledge of social policies and benefits for seniors or even caregivers (Zhou, 2007). However, Ickes and Cottrell (2010) found that college students have adequate health literacy, but still struggle with numeracy questions. These questions are designed to reassure understanding of medical information. College students were able to navigate the health care system, but that was for the college student's health. This process

becomes more complex when dealing with a senior. When looking at insured college students, The Commonwealth Fund (2013) found that 87% of young adults who were uninsured in 2013 would remain uninsured due to the lack of awareness of available marketplaces or a state's inability to expand Medicaid. Following this train of thought, one may conclude that a college student may not be aware or understand the multitude of Medicare/Medicaid qualifications for seniors or what is covered by insurance.

Well-Being

Caregiver well-being is well investigated in the literature. There are numerous physical, psychosocial, and financial problems that arise when a family member provides care for another.

Physical well-being. Caregivers who have depression or other negative affective problems may turn to negative health behaviors in an attempt to handle their situation (e.g., consuming fast food or soda). Hoffman et al. (2012) found that caregivers consumed more soda and fast food than non-caregivers, which put the caregivers at risk for excess morbidity. Along with poor diet, caregiving has been associated with high blood pressure and altered lipid profiles, increasing the mortality rate of caregivers by 63% over a four-year period compared to non-caregivers (Haley, 2003). They also reported that due to the multitude of responsibilities, caregivers are less likely to exercise regularly, which could leave the caregiver susceptible to illnesses. Immune suppression, related to higher levels of stress, can leave the caregiver more susceptible to various diseases (Lisa et al., 2012). Physical symptoms could include immunological disorders, cardiovascular problems (Northouse, Katapodi, Schafenacker, & Weiss, 2012), decreased

time of wound healing (Haley, 2003), and a dependency in order to perform activities of daily life.

Caregiver's tend to minimize their own symptoms or fail to mention any symptoms due to being in the shadow of an illness with a disastrous progression, such as Alzheimer's Disease or Parkinson's Disease (Beach et al., 2005; Carpenter & Mak, 2007; Hendrix, Landerman, & Abernethy, 2013; Murphy, Christian, Caplin, & Young, 2007; Rabinowitz, Saenz, Thompson, & Gallagher-Thompson, 2011; Whitlatch, 2008). If the caregivers' disease progresses, caregivers become weaker, which could lead to hospitalization or even premature mortality. This could increase burden because the ill or hospitalized caregiver has to find someone to carry out the caring duties. For the care recipient, if a caregiver is suffering from a disorder, the quality of the care provided declines, which increases the care recipient's risk for injury or premature institutionalization. This can create more burden for caregivers who have not yet planned for the care recipient's institutionalization.

Unresolved stressors can increase burden, impacting the level of care as well as how the caregiver's reactions to the care recipient. Social support may reduce the impact of burden on caregivers; however, researchers are still unsure of the impact that social support has on burden (Chang, Chiou, & Chen, 2010). Within remote or rural areas, social support services may not be available or unable to meet the needs of the individuals (Morgan, Innes, & Kosteniuk, 2011). Lacking social support and resources, caregivers may begin to "crumble" under the weight of their burden, causing the quality of care to decline (Bastawrous, 2013). Caregivers may also mistreat their care recipient

through verbal abuse or maltreatment, increasing the risk of injury and further burden for the caregiver.

Psychosocial well-being. The high levels of stress have an effect on the caregiver's psychological well-being, such that caregiver's report more negative effects: anger (Blum & Sherman, 2010), depression and anxiety (Blum & Sherman, 2010; Riley & Bowen, 2005), increased emotional distress, and difficulties coping with the new role (Northouse et al., 2012). Because of filial obligation, a caregiver may feel as if there is no choice about the new position, experiencing greater emotional stress and poorer adjustment (Longacre, Ross, & Fang, 2014). Caregivers also are at increased risk of having reduced socializations with neighbors, friends, and others due to being so involved in their responsibilities (Bastawrous, 2013; Haley, 2003). This reduction in their social networks can lead the families to feel isolated and without social support. These negative effects could have significant impact on the caregiver's health, increasing the individual's risk for depression.

Despite the negative psychological affects of caregiving, many caregivers report positive outcomes (Daire, Torres, & Edwards, 2009; Robison, Fortinsky, Kleppinger, Shugrue, & Porter, 2009). Caregivers who are well supported in their endeavors to provide care may report higher levels of emotional satisfaction and positive well-being related to completing caregiving tasks (Otis-Green & Juarez, 2012). Furthermore, Otis-Green and Juarez (2012) state that successful completion of caregiving activities can lead to a stronger dyadic relationship between caregiver and care recipient.

Burden. For several decades, the term "burden" has been difficult to define. In 1980, Zarit et al. defined burden as "a state resulting from the action of taking care of a

dependent or elderly person, a state which threatens the physical and mental health of the caregiver" (as cited in Carretero, Garcés, Ródenas, & Sanjosé, 2009, p. 75). Later, in 1986, George and Gwyther defined burden as "the persistent difficulty to provide care and the physical, psychological, and emotional problems which caregivers or family members can experience when caring for a relative with a disability or some type of deterioration" (as cited in Carretero et al., 2009, p. 75). In an attempt to conceptualize caregiver burden, researchers divided burden into two components: subjective burden and objective burden (Bastawrous, 2013). Subject burden refers to the caregiver's perceptions about the caring situation. More importantly, subjective burden comprises of the attitude and emotional reactions of the caregiver and if the caregiver perceives carrying a burden (Rungreangkulkij & Gilliss, 2000). Objective burden is how dedicated the caregiver is to fulfilling the role in providing care for the care recipient. Included in this burden are the repercussions caring for the family member has on different aspects of the caregiver's life (e.g., social life or leisure; Lisa et al., 2012).

Gazing through a social role lens, role overload and role conflict appear to be related to burden. Role overload occurs when an individual is experiencing pressure from multiple roles at once. Newman and Newman (2007) defined role conflict as attempting to balance the responsibilities of simultaneous roles. As stated above, George and Gwyther defined burden in a multifaceted way, such that caregivers experience difficulty performing caregiving responsibilities, resulting in physical, psychological, and emotional distress. Returning back to social roles, each individual in society performs multiple roles with accompanying expectations. Attempting to balance and execute the multitude of duties in each individual role simultaneously can jeopardize a caregiver by

placing role overload on an already burdened individual: increasing the caregiver's risk of depression. The same path can be taken with role conflict. Caregivers must prioritize responsibilities and constantly modify those prioritizations to accommodate new and existing duties. However, this prioritization may interfere with socially expected roles already in place. For example, a mother of three is providing care for her father. Her eldest child has a ballet recital on the same day as an important medical appointment for her father. Society dictates that she attends both events, but she becomes conflicted and pressured with which event to attend, thus her burden increases.

Tied into the concept of burden is life course's notion of historical time and place. Both members of the caregiving dyad differ in their personal histories. As noted above, it is through these historical experiences that the individual develops. Care recipients may act certain ways because of the experiences they have had, increasing the responsibilities that a caregiver must complete.

Financial well-being. Caregivers experience significant short-term and long-term costs at work: daily disruptions, leaving early, missing work, and frequent interruptions (Gordon & Rouse, 2013; Wakabayashi & Donato, 2005). Depending on the complexity of the caregiving situation, caregivers may change to part-time employment or leave their career altogether in order to provide quality care for their care recipient (Gordon & Rouse, 2013). According to Wakabayashi and Donato (2005), women are those whose work is most affected by caregiving. Women who leave the workforce early or reduce their hours because of caregiving lose $142,697 in wages, $131,351 in Social Security benefits, and at least $50,000 in pensions; a total impact of $324,044 compared to $283,716 for men (Metlife Mature Market, 2011). Single women who provide care have

been found to be 2.5 times more likely to live in poverty in late life (FCA, 2012). Furthermore, of the 65.7 million family caregivers, 37% have children or grandchildren under the age of 18 residing with them as well (Caregiver Action Network, 2014). As of 2013, the average cost of raising a child for a middle-income couple has increased to $245,000 (Hicken, 2014). Depending on the number of children in the house and the medical expenses of the care recipient, this can put serious strain on the caregiver's finances.

Research Questions

1. What are the demographic characteristics of emerging adult caregivers?
2. Among emerging adult caregivers, are increased life events related to psychological affect and burden?
3. When compared with existing research on adult caregivers, do the results of this study show that emerging adult caregivers merit consideration as a classification of family caregivers distinct from other age groups?

Research Hypotheses

Since existing research does not provide a demographic profile of emerging adult caregivers, no specific hypotheses were established for Research Question 1. The following hypotheses were established for Research Question 2.

1. Among emerging adult caregivers, reports of the quantity of transitions will be positively correlated with reports of caregiver burden.
2. Among emerging adult caregivers, reports of the quantity of transitions will be positively correlated with reports of negative psychological affect.

3. Among emerging adult caregivers, reports of the quantity of transitions will be negatively correlated with reports of positive psychological affect.
4. Among emerging adult caregivers, reports of caregiving activity will be positively correlated with reports of caregiver burden.
5. Among emerging adult caregivers, reports of caregiving activity will be positively correlated with reports of negative psychological affect.
6. Among emerging adult caregivers, reports of caregiving activity will be negatively correlated with reports of the positive psychological affect.
7. Among emerging adult caregivers, reports of caregiving activity will be negatively correlated with reports of caregiver well-being.

No hypotheses were established for Research Question 3 since this will involve reporting statistics in studies of older caregivers on the variables and demographics to identify areas where potential differences may be present. Descriptions of how the research constructs will be measured can be found in Table 1.

Table 1

Descriptions of how research constructs will be measured.

Constructs	Type	Description
Age	Continuous	Self-reported data to determine each caregiver's age at the time of the survey.
Caregiver type	Categorical	Self reported data to determine each caregiver's level of involvement (viz., primary, secondary, or tertiary). Categories are based on previous research.
Caregiving activity	Continuous	Individual scores will be computed on Likert scale data.
Well-being	Continuous	Individual scores will be computed on Likert scale data.
Health literacy	Continuous	Individual scores will be computed on Likert scale data.
Burden	Continuous	Mean scores on self-reported continuous scales will be computed to determine each caregiver's categorical level of burden (*viz.,* low, mild, moderate, severe). Categories will be determined using those provided by the test developers.
Transitions	Continuous	Individual scores will be computed on self-reported data.
Psychological affect	Continuous	Mean scores on self-reported continuous scale will be computed to determine each caregiver's positive and negative psychological affect.
Caregiver role	Categorical	Caregiver responses will be used to evaluate caregiver's identification as a caregiver.

CHAPTER III

METHODOLOGY

Sample

The sample for this study was a convenient sample of students recruited from large undergraduate university courses. The sample criteria for this study were that participants be undergraduate students, enrolled in an Oklahoma State University (OSU) course, and between the ages of 18 and 25. The target minimum was 150 self-identified caregivers; however saturation was reached at 130 caregivers. Of those, 12 cases were dropped due to missing data.

Recruitment and Data Collection

Data was collected using four established and validated scales and two original scales developed for the purposes of this study. These tools were used to assess the constructs of caregiving activity, caregiver well-being, positive and negative psychological affect, health literacy, caregiver burden, and transitions. Four open-ended questions were used to obtain qualitative data on the caregivers' personal definition of a family caregiver, as well as the personal sacrifices of providing care. Furthermore, four open-ended questions were used to gather qualitative data on the experiences of providing care for multiple care recipients. The survey (see Appendix A) took approximately 30 minutes to complete and was administered on paper. All procedures

were approved by Oklahoma State University's Office of Research Compliance (Institutional Review Board) before recruitment or data collection began.

Measures

Six scales were used in this study; two were developed for the purpose of this study. These measures can be found in Appendix A.

Caregiving activity. Caregiving activity scores were obtained through a measure developed by the researcher. This scale is divided into two subscales: activities of daily living and instrumental activities of daily living. The scale is composed of 12 items in total, including six questions in each subscale. Each question is on a four-point scale ranging from 'do not help' to 'help a lot'. Scores are interpreted using the following categories: non-caregiver (0); tertiary caregiver (1-12); secondary caregiver (13-24); and primary caregiver (25-36). Validity and reliability scores will be calculated for this measure. The measure was used consistently and the questions were kept intact.

Well-being. The Caregiver Well-being Scale-Short Form (CWBS-SF) is composed of 16 items in total and contains two dimensions: basic needs and activities of daily living (Tebb, Berg-Weger, & Rubio, 2013). Under basic needs, three topics emerge: physical needs (three questions; α=0.66), emotion (three questions; α=0.49), and self-security (two questions; α=0.22). Activities of daily living range from self-care (four questions; α=0.81), connections (two questions; α=0.55), and time for self (2 questions; α=0.80). Each item is rated on a five-point scale ranging from 'rarely' to 'usually'. Reliability was calculated for the scale at an overall total of 0.83.

Burden. The Zarit Burden Interview (ZBI) will be used to assess burden in participants. This scale contains 22 items on a five-point scale ranging from 'not at all' to

'extremely' (Zarit, Reever, & Bach-Peterson, 1980). Overall scores are calculated by totaling the scores with higher scores representing higher levels of burden. Scores are then interpreted with the following categories: little or no burden (0-20); mild to moderate burden (21-40); moderate to severe burden (41-60), and severe burden (61-88; Hébert, Bravo, & Préville, 2000). The ZBI has been found to have construct validity and has a calculated reliability of 0.88-0.91.

Psychological affect. Scores were obtained using the Positive and Negative Affect Schedule (PANAS; Watson, Clark, & Tellegen, 1988). This scale is composed of 20 items on a five-point scale that ranges from 'very slightly or not at all' to 'extremely'. Scores range on both scales from 10 – 50. Positive affect scores are found by adding the ten items designated for positive affect (e.g., items 1, 3, 5, 9, 10, 12, 14, 16, 17, and 19 on the original scale); higher scores represent higher scores of positive affect. Negative affect scores are found by adding the ten items designated for negative affect (e.g., items 2, 4, 6, 7, 8, 11, 13, 15, 18, and 20 on the original scale); lower scores represent lower levels of negative affect. The scale has been found to have construct validity. Reliability was found to be 0.82-0.85 for the positive items and 0.83-0.86 for the negative items (Watson et al., 1988).

Health literacy. Scores will be obtained through an original measure to assess an informal caregiver's ability to comprehend issues related to the care recipient's health. This scale is divided into three sections: social services, medical, and care recipient to assess the caregiver's medical understanding at the time of obtaining the caregiving role. The scale is composed of 9 items in total. Each question is on a four-point scale ranging

from ‘strongly disagree’ to ‘strongly agree’. Validity and reliability scores will be calculated for this measure using Cronbach’s alpha and inter-item reliability.

Transitions. Scores will be obtained by using a modified version of the Life Experiences Survey (LES). This assessment contains 60 items that assess the various life events that an individual has experienced (Sarason, Johnson, & Siegel, 1978). The participant will be asked to indicate the which life events were experienced within the last few years. Reliability for the original measure was found to be 0.53 for the positive change and 0.88 for the negative change. For the purpose of this study, the emotional impact of the life events was removed from the scale. Reliability for the modified measure was found to be 0.88.

Open-ended questions. Two open-ended questions were developed to obtain the participant’s views on the caregiving role. The two items are: “Before today, did you identify yourself as a caregiver? Why?” and “Is there any thing(s) (extracurricular activities, employment, aspirations, etc.) that you have had to alter or give up since taking on your role a caregiver? Please list.”

The demographic items were age, gender, race, major, and employment status. Several items were about the caregiving relationship, such as how long the caregiver has been providing care, how often the caregiver provides care, who the caregiver is providing care for, and if the care recipient lives with the caregiver.

Analytic Plan

All data was entered into SPSS 14.0 prior to analyses. The scores on the measures involving more than one item were established as described in the measurement section. Cronbach’s alpha reliability coefficients were established for each measure. Figure 1

depicts the relationship between the study's research constructs as informed by the literature. The basis of Research Question 2 and the research hypotheses were founded using the relationships found in Figure 1.

The analysis of Research Question 1 involved establishing descriptive statistics (means, ranges, and/or percentages) as appropriate for the demographic items on the questionnaire.

The analysis of Research Question 2 and the corresponding Research Hypotheses (1 - 7) involved conducting a series of bivariate correlations among the following variables as specified in the above hypotheses: quantity of transitions, caregiver burden, negative psychological affect, positive psychological affect, and caregiving activity.

The analysis of Research Question 3 involved comparing the results of this study on caregiving activity, caregiver well-being, psychological affect, caregiver burden, and transitions to conceptually determine if the results are distinct from those reported in selected earlier research studies of caregivers of older age groups. No statistical analyses were conducted.

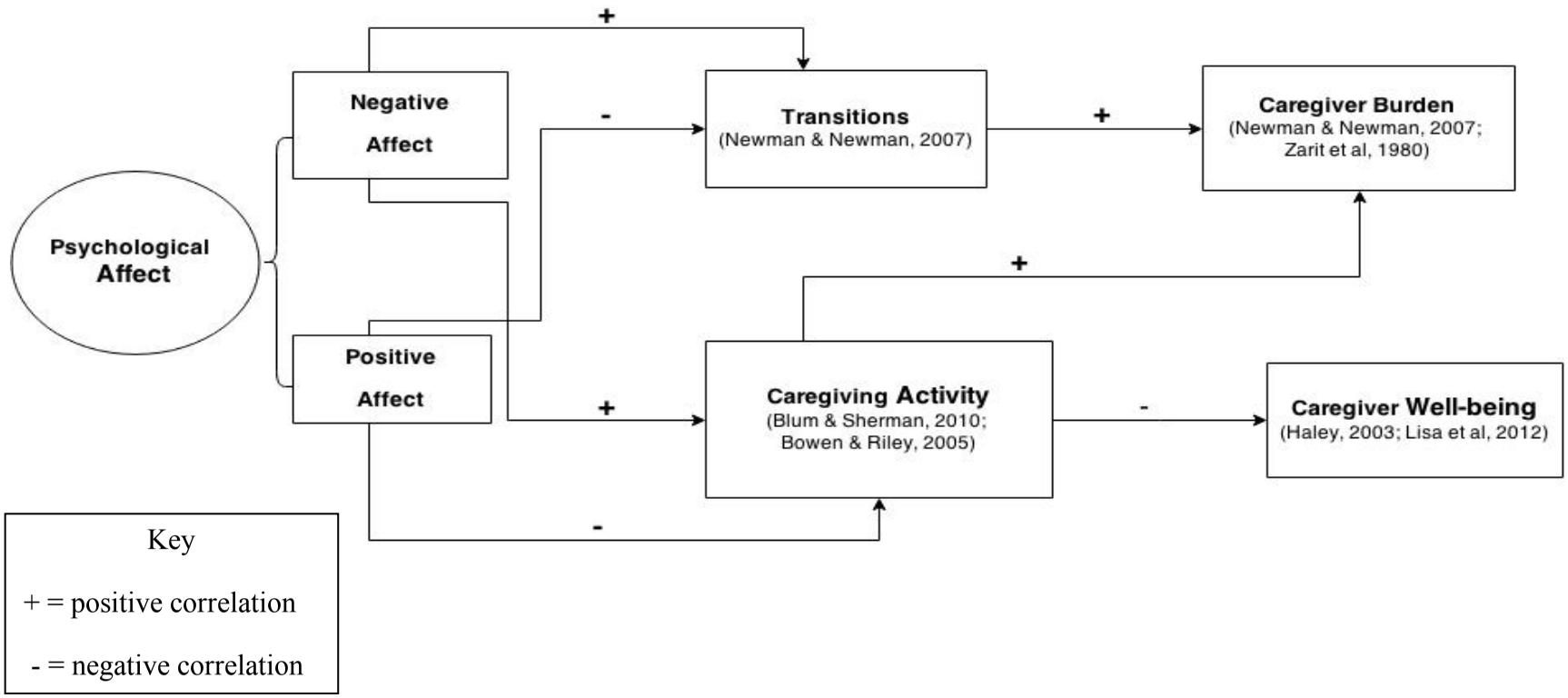

Figure 1. Relationships between research constructs.

CHAPTER IV

RESULTS

Demographics

Given that research question one was to determine the demographic characteristics of emerging adulthood caregivers, this section addresses the demographic portrait of emerging adulthood caregivers. Forty-four percent of the 118 respondents reported that they were currently providing care. Almost 91% of the sample reported providing care at some time before the study. Over a third of the caregivers (37%) provided care simultaneously for multiple care recipients. The average number of care recipients for multiple caregivers was 1.24. The average age was 20.13. The sample was a diverse group of all majors with several academic colleges represented.

Caregivers were most likely to either provide care for less than six months or more than five years (18% and 17% respectively). Twelve percent provided care for six to 11 months, as well as one to three years. Fourteen percent did not provide a time span. Caregivers were more likely to be unemployed than employed (57% vs 40%). Of those employed, caregivers were most likely to work various shifts (22%) and experienced no change in their employment (81%).

Almost three-fourths of the sample were white (74%), 6% were African American, 3% were Latino, 7% were Asian American, 2% were Native

American/Alaskan Native, and 8% described themselves as multiracial. Caregivers were more likely to be single (79%) and female (78%). Frequency and percentages of the above mentioned variables can be found in Table 2. Care recipients were typically either immediate family members or close social peers. See Table 3 for the care recipient frequencies and percentages.

Six scales were used in this study. They were the Caregiving Activity Scale, Caregiver Well-being Scale, Zarit Burden Interview, Positive and Negative Affect Schedule, Health Literacy Scale, and Life Events scale. Mean, standard deviation, and range for each scale are reported by age group in Table 4.

Reliability

Six scales were used in this study. Of those, four were already validated: the Caregiver Well-Being scale (α=0.83); the Zarit Burden Interview (α=0.88-0.91); the Positive and Negative Affect Scale (α=0.82-0.85 for the positive items; α=0.83-0.86 for the negative items); and the Life Experiences Survey (α=0.88). The Caregiver Activity Scale and the Health Literacy scale were developed for this study.

The Caregiver Activity Scale had a Cronbach's alpha that was calculated at 0.87 ($p < 0.05$). The scale mean was calculated at 14.03 and a standard deviation of 9.473 with a variance of 89.742. This scale, using a four-point Likert scale, was created because all other scales measuring caregiving activity did not use a Likert scale to measure how much activity the caregiver completed.

The Health Literacy Scale had a Cronbach's alpha that was calculated at 0.954 ($p < 0.05$). The scale mean was calculated at 21.52 with a standard deviation of 9.187 and a

variance of 84.406. This scale was created because no health literacy scaled existed to measure the variables that the researchers wanted to measure.

Results of Hypotheses

Seven hypotheses were tested for this study, each using bivariate correlations. Results of these correlations are reported in Table 5.

Hypothesis 1. Among emerging adult caregivers, reports of the quantity of transitions will be positively correlated with reports of caregiver burden. A nonsignificant correlation of 0.17 (p = n.s.) was found between quantity of transitions and caregiver burden, thus the hypothesis was rejected.

Hypothesis 2. Among emerging adult caregivers, reports of the quantity of transitions will be positively correlated with reports of negative psychological affect. Hypothesis two was rejected. No significant correlation (r = -0.16; p = n.s.) was found between quantity of transitions and negative psychological affect.

Hypothesis 3. Among emerging adult caregivers, reports of the quantity of transitions will be negatively correlated with reports of positive psychological affect. Hypothesis three was rejected due to a nonsignificant correlation of r = 0.05 (p = n.s.) between quantity of transitions and positive psychological affect.

Hypothesis 4. Among emerging adult caregivers, reports of caregiving activity will be positively correlated with reports of caregiver burden. Caregiving activity and caregiver burden were significantly correlated, $r = 0.26$, $p < 0.01$.

Hypothesis 5. Among emerging adult caregivers, reports of caregiving activity will be positively correlated with reports of negative psychological affect. No significant

correlation (r = 0.06; p = n.s.) was found between caregiving activity and negative psychological affect. Hypothesis five is rejected.

Hypothesis 6. Among emerging adult caregivers, reports of caregiving activity will be negatively correlated with reports of the positive psychological affect. No significant correlation (r = 0.07; p = n.s.) was found between caregiving activity and positive psychological affect. Hypothesis six is rejected.

Hypothesis 7. Among emerging adult caregivers, reports of caregiving activity will be negatively correlated with reports of caregiver well-being. No significant correlation (r = 0.14; p = n.s.) was found between caregiving activity and caregiver well-being. Hypothesis seven is rejected.

Research Question 3 will be addressed in the discussion.

Summary of Results

Emerging adulthood caregivers, on average, provided care for less than six months or more than five years. Care recipients consisted mainly of immediate family members or close personal friends. The care was typically provided before the survey was administered. Among this sample of 118 emerging adulthood caregivers, results show that unemployed, single, white females are more likely to provide care. Quantity of transitions was not found to influence psychological affect or caregiver burden. Not surprisingly, caregiving activity was correlated with caregiver burden such that higher levels of burden were correlated with higher levels of burden. However, caregiving activity was not correlated with well-being or psychological affect.

Table 2

Emerging adult caregiver demographics.

Variable	N	Percentage
Provision of Care		
Current Caregivers	52	44.1
Past Caregivers	107	90.7
Multiple Care Recipients	37	31.4
Age		
18	22	18.6
19	29	24.6
20	23	19.5
21	21	17.8
22	12	10.2
23	5	4.2
24	2	1.7
25	4	3.4
Length of Care		
Less than 6 months	21	17.8
6 to 11 months	14	11.9
1 to 3 years	15	12.7
3 to 5 years	15	12.7
More than 5 years	20	16.9
Do not know	10	8.5
Choose not to answer	4	3.4
Employment		
Part-time	47	39.8
Leave of absence	2	1.7
Unemployed	67	56.8
Ethnicity		
White	87	73.7
African American	7	5.9
Latino	4	3.4
Asian American	8	6.8
Native American/Alaska Native	2	1.7
Multiracial	9	7.6
Relationship Status		
Married	6	5.1
Spouse/Partner	13	11
Separated	1	0.8
Living Together	4	3.4
Single	93	78.8
Gender		
Male	24	20.3
Female	92	78

Table 3

Care recipient frequencies and percentages.

Variable	N	Percentage
Care Recipients		
Current		
Family		
Siblings	12	21.8
Parent	5	9.1
Cousin	1	1.8
Grandparent	7	12.7
Great Aunt/Uncle	2	3.6
Niece/Nephew	4	7.3
Child	1	1.8
Stepparent	1	1.8
Peers		
Friend	15	27.3
Girlfriend	2	3.6
Roommate	1	1.8
Classmate	1	1.8
Babysat	3	5.5
Past		
Family		
Siblings	25	23.8
Parent	17	16.2
Cousin	4	3.8
Grandparent	24	22.9
Great Grandparent	4	3.8
Niece/Nephew	9	8.6
Child	2	1.9
Peers		
Friends	19	18.1
Roommate	1	1.0

Table 4

Scale means based on age.

		Caregiving Activity	Caregiver Well-being	Burden	Positive Affect	Negative Affect	Health Literacy	Transitions
18								
	Mean	13.26	59.76	13.38	33.35	21	22.05	11.6
	N	19	21	21	20	21	19	15
	Std. Dev	8.39	10.21	7.9	7.54	5.35	5.89	6.15
	Range	36.00	36.00	27.00	30.00	26.00	21.00	25.00
19								
	Mean	12.32	62.83	15.85	32	18.1	24.24	14.65
	N	25	29	27	29	29	25	23
	Std. Dev	8.46	9.37	15.57	9.61	6.59	7.67	7.16
	Range	26.00	31.00	45.00	35.00	21.00	27.00	25.00
20								
	Mean	16.91	60	14.75	31.41	19.45	23.9	15.21
	N	22	22	20	22	22	20	14
	Std. Dev	8.62	9.76	10.37	10.33	8.01	6.87	7.36
	Range	32.00	48.00	35.00	37.00	30.00	23.00	28.00
21								
	Mean	16.48	60.14	18.11	33.67	21.19	25.18	18.1
	N	21	21	19	21	21	17	10
	Std. Dev	10.99	10.28	15.04	8.65	8.48	6.48	8.25
	Range	36.00	33.00	48.00	34.00	33.00	25.00	27.00
22								
	Mean	16.18	56.09	22	33.17	19.91	23.55	24.5
	N	11	11	10	12	11	11	8
	Std. Dev	10.6	10.23	15.83	9.06	6.07	4.63	7.69
	Range	31.00	30.00	43.00	29.00	20.00	16.00	25.00

		Caregiving Activity	Caregiver Well-being	Burden	Positive Affect	Negative Affect	Health Literacy	Transitions
23								
	Mean	13.8	64.2	15.75	27.2	17.2	29.5	23.5
	N	5	5	4	5	5	4	4
	Std. Dev	11.8	15.55	7.41	14.13	4.87	10.5	8.27
	Range	28.00	38.00	17.00	34.00	12.00	22.00	17.00
24								
	Mean	11	56	13	38	17.5	23.5	0
	N	2	2	2	2	2	2	0
	Std. Dev	8.49	7.07	2.83	8.49	0.71	3.54	0
	Range	12.00	10.00	4.00	12.00	1.00	5.00	0
25								
	Mean	12.75	51.5	22	30.5	15	23.5	0
	N	4	4	4	4	4	4	0
	Std. Dev	12.12	9.11	14.35	4.51	2.16	5.26	0
	Range	26.00	21.00	33.00	10.00	5.00	12.00	0
Total								
	Mean	14.66	51.5	16.31	32.39	19.47	24.01	16.15
	N	109	115	107	115	115	102	74
	Std. Dev	9.42	10.16	12.84	9.14	6.84	6.65	8.09
	Range							

Table 5

Correlations for Hypotheses 1-7

	Transitions	Burden	Negative Affect	Positive Affect	Caregiver Well-being	Caregiving Activity
Transitions	-					
Burden	0.170	-				
Negative Affect	-0.163	0.212*	-			
Positive Affect	0.049	-0.212*	-0.095	-		
Caregiver Well-being	0.100	-0.368**	-0.212*	0.338**	-	
Caregiving Activity	0.161	0.264**	0.063	0.069	0.140	-

*p < 0.05. **p < 0.01.

CHAPTER V

DISCUSSION

The purpose of this study was to explore an understudied caregiving population by examining the characteristics of emerging adult caregivers. By sketching this population, it becomes easier to denote the differences and similarities between emerging adulthood caregivers and middle and late adulthood caregivers. It is important to note that the portrait of this caregiving population is drastically different from middle and late adulthood caregivers. The literature paints a picture of a 50-year-old woman (FCA, 2012). This woman experiences the demands of caring for her aging parents, as well as caring for her own children (e.g., sandwich generation). Furthermore this woman is juggling her familial responsibilities along with her career; leaving little time for leisure pursuits or social events (Bastawrous, 2013). Feelings of anxiety and isolation plague her (Blum & Sherman, 2010; Haley, 2003; Longacre et al., 2014). Standing back, the outcome looks bleak. However, when considering the portrait of emerging adults, the image changes. The depiction, again, is of a female, yet she is not as burdened by her responsibilities as her aged counterpart. Her care recipients include older family members, but more likely include siblings or friends, and unburdened with the load of a career.

Comparing the two images, it is easy to see that they are drastically different. This difference lies not only in the developmental period that the caregiver is in, but also who the care recipient is. Adult caregivers are typically providing care for spouses or aging parents (Semiatin & O'Connor, 2012). However, when looking at these data, emerging adults may provide care for parents or grandparents, but the majority of care is provided to siblings or friends. Participants indicated that they typically provide emotional care for their care recipient, with little to no assistance with activities of daily living or instrumental activities of daily living. With little day-to-day responsibilities, the demands are less, in comparison to older caregivers, thus emerging adulthood caregivers are able to engage in other pursuits (i.e., higher education, social events, etc.).

From a life course perspective, this sample of emerging adulthood caregivers would be considered "on-time." The emerging adulthood caregivers did not put off their role as a college student; leaving them better able to keep pace with their non-caregiving peers in assuming college roles. As indicated by the non-significant correlation between caregiver burden and quantity of transitions, many emerging adulthood caregivers were progressing through transitions with little difficulty. Few caregivers experienced loss in intimate relationships (e.g., friends or dating relationships). Participants indicated that they did not have to rearrange their social schedules to provide care. This is in stark contrast to the literature on mid and late life caregivers, which reveals higher rates of depression, anxiety, social isolation (Bastawrous, 2013; Blum & Sherman, 2010; Haley, 2003).

Middle and late adulthood caregivers are more likely to be the primary caregiver (Day, n.d.), while emerging adulthood caregivers are more likely to hold the secondary or

tertiary caregiver role. Emerging adulthood caregivers provided care based on need from the primary caregiver. Several participants indicated that they would assist their family member with the caregiving responsibilities when the primary caregiver requested assistance. This provision of care on a need basis allows the caregiver to fulfill their other roles (e.g., student, friend, etc.). This study did not solely focus on primary caregivers, so the results of this study are not applicable to primary emerging adulthood caregivers. However, that does not diminish the results of this study. Results have shown that secondary and tertiary caregivers can still be affected by the influences of caregiver burden.

Health Literacy

The health literacy questions in the study were designed to measure how much the students knew about navigating the aging network and if they could apply their knowledge in a professional setting, such as a medical office. The overall health literacy scores for the sample were high, supporting Ickes and Cottrell (2010) work that emerging adults have adequate health literacy knowledge. However, it has been shown that emerging adults have poor knowledge of age-associated illnesses (Kwok et al., 2011). The high score could be indicative of the participant's assumption that the individual could fulfill that role if needed. It could be speculated that the caregiver assumes that he or she could know what to ask based on their experiences with the care recipient. Navigating Medicaid/Medicare and awareness of available social services received the lowest scores; supporting Kwok et al. (2011) findings that college students do not understand the aging network. Further research would be needed to determine if the

caregiver is self-based on experiences with the care recipient or based on their own experiences with a health professional.

Well-being

Well-being has been previously linked to caregiver burden (Lisa et al., 2012; Riley & Bowen, 2005). The results of this study support the link between caregiver well-being, caregiver burden, and psychological affect. In this sample, caregiver well-being was negatively correlated with caregiver burden and negative psychological affect. Due to the secondary or tertiary role as a caregiver, the day-to-day responsibilities as a caregiver do not negatively impact the emerging adulthood caregivers, unlike the middle and late adulthood caregivers. By having extra time to themselves, emerging adulthood caregivers are able to have balanced meals, exercise, and socialize with peers; supported by the positive correlation between well-being and positive psychological affect.

While there were significant differences in the portraits of the two groups, there are some similarities. As noted above, both are likely to be female. Additionally, both emerging and middle adulthood caregivers may have trouble planning financially for their future. Middle adulthood caregivers typically pay out-of-pocket medical expenses (MetLife Mature Market, 2011); depleting their personal savings. This depletion could negatively impact their retirement plans. Emerging adulthood caregivers are typically unemployed, receiving monetary support from parents or the care recipient. Without a steady income, these caregivers are unable to plan for their future, postponing major transitions such as marriage, owning a home, or procreation. This could also affect their prospects for employment because they do not want or cannot afford to move far from the care recipient; further limiting the emerging adulthood caregiver's career prospects.

Interpreting the Hypotheses

It was hypothesized that quantity of transitions would be positively correlated with caregiver burden. However no significant correlation was found between the quantity of transitions and caregiver burden. The results of this study do not support the link between role overload or role strain and caregiver burden. This non-significant result could be indicative of emerging adulthood caregivers' roles, typically, as either secondary or tertiary caregivers. Because these caregivers are not providing continuous daily care for an extended period of time, they do not have to attempt to juggle their numerous roles with their caregiving responsibilities. Hypothesis two stated that quantity of transitions would be positively correlated with negative psychological affect. The data found no significant correlation between the two variables. Furthermore, hypothesis three stated that positive psychological affect would be negatively correlated with quantity of transitions. However no significant correlation was found between these two variables as well. The results of hypothesis two and three do not support the link between role overload or role strain and psychological distress, indicative of the caregiver's role as either a secondary or tertiary caregiver. Caregivers reported no psychological distress with their numerous roles, thus they were not experiencing role strain or role overload. It is important to note, however that the life events scale did not include the emotional impact of each life event on the scale, thus the time between when the event occurred and when the survey was administered could have altered the participant's mood state.

Caregiving activity was hypothesized to be positively correlated with caregiver burden. Results found a significant correlation between the two variables. Previous research has shown a link in primary caregivers between caregiving activity and caregiver burden (Bastawrous, 2013; Carretero et al., 2009). Even though the emerging adulthood caregivers typically do not perform the primary caregiving role, the individuals occupying the secondary and tertiary roles can still experience strain or overload. Hypothesis five stated that caregiving activity would be positively correlated with negative psychological affect. No significant correlation was found between negative psychological affect and caregiving activity. Additionally, hypothesis six stated that caregiving activity would be negatively correlated with positive psychological affect. The data found no significant correlation between the two variables. The results from hypothesis five and six are surprising in that the non-significant correlations do not support the link between caregiving activity and psychological affect. As noted above, caregiving activity has been linked to psychological affect (Blum & Sherman, 2010; Northouse et al., 2012). However, no direct relationship was found between the two variables. The link between caregiving activity and psychological affect could be mediated by caregiver burden. As shown in Table 4, psychological affect was found to be significantly correlated with caregiver burden.

Hypothesis seven stated that caregiving activity would be negatively correlated with caregiver well-being. Results found no significant correlation between well-being and caregiving activity; unsupportive of the literature. Emerging adulthood caregivers may experience caregiver burden, but due to their roles as secondary or tertiary caregivers, as well as being unemployed, they are left with free time to ensure that they

can take care of themselves. Caregivers reported eating well and exercising frequently. The stress of providing care does not appear to have a negative impact on the caregiver's well-being.

Circling back to life course theory, the number of experienced transitions was not found to be correlated with burden or psychological affect. These findings support the viewpoint that the emerging adulthood caregivers are not disrupted developmentally because they are not experiencing negative consequences while undergoing transitions. As mentioned earlier, emerging adulthood caregivers did not report feeling "off-time" from their non-caregiving peers; experiencing little to no disruption in their transitions. Furthermore, emerging adulthood caregivers were born into a technological era that has increased technological use. According to Charness and Boot (2009), 18-29 year olds have the highest percentage of computer usage across the lifespan; this also includes the use of the Internet. It can be speculated that emerging adulthood caregivers could access information about and services for caregivers quicker and easier than middle and late adulthood caregivers. Well-being was negatively correlated with burden supporting the principle that individuals act in their own best interest. Even though emerging adulthood caregivers are providing care and it can be burdensome, they are still partaking in opportunities, such as social events or higher education, that appear to offset the more negative consequences of caregiving.

Limitations

Several limitations to this study should be noted. The sample was collected on a college campus, excluding caregivers who are fulfilling the primary caregiving role and unable to attend higher education. Those represented in this sample were individuals who

provided care on an occasional basis and were able to attend college. The classes used for this study were also gender skewed; containing more females than males. The non-significant results of this study may be a product of the measures used. Scales developed to assess caregiving variables are designed with middle and late adulthood caregivers as the target population. As noted above, emerging adulthood and middle and late adulthood caregivers are in different developmental periods. Items developed for one caregiving population may not be applicable to the other caregiving population. Due to the subject nature of the questions, some respondents may have responded in a more positive light to achieve social approval, despite the anonymity of the survey.

Operationalization of Caregiving

Research (Smyth et al., 2011) has shown that caregivers tend to underreport caregiving activities. The incidence of caregiving is underreported due to the notion that caregivers do not identify themselves as a *caregiver* (Smyth et al., 2011). These individuals believe that caregiving is just an extension of a previous role (e.g., child, sibling, etc.), modifying their definition of the former role to include caregiving responsibilities. Furthermore, even though the term caregiver was operationalized for the participants, many either incorporated their own definition of caregiving, based their definition off of past experience, or misunderstood the definition. Following the literature, when asked if the participant identified himself or herself as a caregiver before taking the survey, many said that they did not identify themselves as one. Several participants viewed their role as an extension of a former role. "…I'm her daughter" "…that's my mom. I did it out of love." Others mentioned that they did not identify themselves as a caregiver because of the time frame in which care was provided. "…it

wasn't long term" "[not] because of the infrequency." Several participants adapted a definition of caregiving from a previous experience or social role and applied it to their current situation. "…because I have always babysat and/or worked in childcare." "…I wasn't getting paid and not a frequent caregiver."

As mentioned earlier, O'Connor (2007) states that positions bestow a set of flexible rights. This is reflected in the above statements. Emerging adulthood caregivers accepted their roles as caregivers, but instead of accepting the identification as a caregiver, they incorporated the caregiving responsibilities into a former role (e.g., child, friend, etc.); becoming flexible in how they identify themselves. Even when asked if they considered themselves as a caregiver after the survey, most still did not. They adhered to their position of familial obligation and reciprocity; assimilating new societal expectations (i.e., providing care) into an earlier established role.

Recommendations

Research. Further research is needed to develop a more complete profile of emerging adulthood caregivers. This study provided a stepping stone in developing that profile; however future research needs to focus on primary emerging adulthood caregivers to determine the risks and benefits that this population experiences. Future research should also explore the impact of assuming a caregiving role early in life on family expectations later in life. According to the NCA and AARP (2015), caregivers reported expecting to take on another caregiver role in the future. The fundamental question to be answered is if once a caregiver assumes the caregiving role, does the caregiver's family define that individual as the "family's caregiver" for future individuals requiring care? By understanding how families determine caregivers, researchers can

develop educational programs to educate families about caregiving as a familial responsibility, rather than an individual responsibility.

A universal definition of caregiving needs to be constructed to provide a more objective measure. By universally defining this term, less confusion would abound around this topic. Various fields use the term caregiver (e.g., early childhood education, human development and family science, etc.), thus a centralized definition denoting a family caregiver would be beneficial. Furthermore, research has indicated the caregivers either reduce the number of hours worked or transition out of employment (FCA, 2012). Geographical proximity to the care recipient, as well as care needs can limit career prospects. Understanding the impact caregiving has on the caregiver's employment is also another future research concern.

Practice. Many caregivers do not identify themselves as a caregiver, nor know about social services designed for them. Education about the role as a caregiver would allow caregivers to identify themselves early on as a caregiver. This study has implications for youth programs. For example, working with 4-H programs through state extension programs can provide access to individuals who are unfamiliar with caregiving so that they can be educated about this topic and be aware of the consequences and demands of providing care. This study incorporated individuals across all disciplines, yet relatively few participants knew of available social services.

Furthermore, caregivers should be educated about age-associated illnesses, regardless of field of study. By educating individuals sooner, they can be better prepared to assume the caregiver role; lowering their risk of physical and psychological distress (i.e., anxiety or depression). As the profile of emerging adulthood caregivers emerges,

social services need to be adapted or developed to reach this population. Respite services usually require advance notice to obtain a respite caregiver, yet this age group does not typically schedule social events (e.g., going to the movies, hanging with friends, etc.) weeks in advance. Thus services will need to be flexible to accommodate the spontaneity of this population.

Conclusion

The purpose of this study was to explore common family caregiver characteristics of an understudied caregiving population. Because of the little research on emerging adulthood caregivers, this study provides a glimpse into this population by comparing the experiences of emerging adulthood caregivers to the experiences of middle and late adulthood caregivers. From this study, future research can focus on primary emerging adulthood caregivers to determine how caregiving impacts their development and day-to-day life. Social services can begin to be developed or adapted to fit the flexibility and spontaneity of the emerging adulthood population.

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APPENDICES

Appendix A

Survey

Survey

The aim of this study is learn more about how family members help each other out. The first thing we need to do is have you tell us which one of these best describes you:

1. Are you currently providing care (any type of physical and/or emotional care without pay**) to a family member or close friend?**	Yes	No
1a. How old is this individual?		
1b. What is your relationship to this individual?		
2. Have you ever provided care (any type of physical and/or emotional care without pay) **for a family member or a close friend?**	Yes	No
2a. How old was this individual when you began providing care?		
2b. What is your relationship to this individual?		

Included below are a few definitions to provide some assistance.

Informal caregiver: an individual who provides any type of physical and/or emotional care for a family member or a friend, without compensation (salaried position/hourly wage).
Care recipient: the individual who receives care from the informal caregiver.

If you have not provided care for multiple family members or close friends, please skip to page 4.

1. Did you provide care (any type of physical and/or emotional care without pay) for 2 or more family members or close friends at the same time?	Yes	No
2. How many family members or close friends have you provided care (any type of physical and/or emotional care without pay) for?		
3. How old are/were these persons?		
4. What are/were your relationships to those persons?		

5. Please answer the following open-ended questions as complete as possible. Please print clearly. If you run out of space, please feel free to write in the blank space at the end of page 4. Be sure to indicate the question you are answering.

   A. Briefly explain how you came to provide care multiple individuals.

   B. What skills have you had to develop to provide care for multiple care recipients?

Multiple Care Recipients (cont.)

C. Do you feel providing care for multiple care recipients was more complicated? Please explain.

D. Did your experiences with one care recipient help you with the other(s)? If yes, what helped you?

1. Please indicate how much help you provide for your care recipient:

	Do not help	Slight Help	Moderate Help	A lot of help
Bathing	0	1	2	3
Toileting	0	1	2	3
Dressing	0	1	2	3
Eating	0	1	2	3
Grooming	0	1	2	3
Getting Up	0	1	2	3
Shopping	0	1	2	3
Finances	0	1	2	3
Transportation	0	1	2	3
Laundry	0	1	2	3
Housework	0	1	2	3
Preparing Meal	0	1	2	3

What other duties do you fulfill?

2. As you read and carefully reflect on your life in the past several months, indicate to what extent each of YOUR needs has been met. Circle the most accurate number for each need listed below:

	Rarely	Seldom	Sometimes	Often	Almost Always
Eating a well balanced diet	1	2	3	4	5
Getting enough sleep	1	2	3	4	5
Receiving appropriate health care	1	2	3	4	5
Expressing love	1	2	3	4	5
Expressing anger	1	2	3	4	5
Feeling good about yourself	1	2	3	4	5
Feeling secure about your financial future	1	2	3	4	5
Having adequate shelter	1	2	3	4	5
Buying food	1	2	3	4	5
Taking care of personal daily activities (meals, hygiene, laundry)	1	2	3	4	5
Attending to medical needs	1	2	3	4	5
Keeping up with home maintenance activities (lawn, cleaning, house repairs, and so forth)	1	2	3	4	5
Participating in events at church and/or in the community	1	2	3	4	5
Taking time to have fun with friends and family	1	2	3	4	5
Treating or rewarding yourself	1	2	3	4	5
Making plans for your financial future	1	2	3	4	5

3. Please circle the response that best describes how you feel.

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
Do you feel that your relative asks for more help than he/she needs?	0	1	2	3	4
Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4
Do you feel stressed between caring for your relative and trying to meet other responsibilities for you family or work?	0	1	2	3	4
Do you feel embarrassed over your relative's behavior?	0	1	2	3	4
Do you feel angry when you are around your relative?	0	1	2	3	4
Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?	0	1	2	3	4
Are you afraid what the future holds for your relative?	0	1	2	3	4
Do you feel your relative is dependent on you?	0	1	2	3	4
Do you feel strained when you are around your relative?	0	1	2	3	4
Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
Do you feel that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4
Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4
Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0	1	2	3	4
Do you feel that you don't have enough money to take care of your relative addition to the rest of your expenses?	0	1	2	3	4

Question 3 Continued	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4
Do you wish you could leave the care of your relative to someone else?	0	1	2	3	4
Do you feel uncertain about what to do about your relative?	0	1	2	3	4
Do you feel you should be doing more for your relative?	0	1	2	3	4
Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4

4. Please indicate to what level you agree with the following statements:

When I became a caregiver:	Strongly Disagree	Disagree	Agree	Strongly Agree
I understood my care recipient's condition	1	2	3	4
I know about available social services I could use	1	2	3	4
I was confident in talking to the medical staff (physicians, nurses, etc.) about my care recipient's condition	1	2	3	4
I knew the doses of my care recipient's medication(s).	1	2	3	4
I knew how to navigate Medicare and Medicaid.	1	2	3	4
I understood the medical staff when he or she explained my care recipient's medical issues and needs.	1	2	3	4
I knew when to administer medications	1	2	3	4
I knew the benefits my care recipient can receive	1	2	3	4
I was confident in handling all the medical requirements to assist my care recipient.	1	2	3	4

5. **This scale consists of a number of words that describe different feelings and emotions. Read each item and then indicate to what extent you feel this way right now, that is, at the present moment OR indicate the extent you have felt this way over the past week.**

	Very Slightly or Not at all	A Little	Moderately	Quite a Bit	Extremely
Interested	1	2	3	4	5
Distressed	1	2	3	4	5
Excited	1	2	3	4	5
Upset	1	2	3	4	5
Strong	1	2	3	4	5
Guilty	1	2	3	4	5
Scared	1	2	3	4	5
Hostile	1	2	3	4	5
Enthusiastic	1	2	3	4	5
Proud	1	2	3	4	5
Irritable	1	2	3	4	5
Alert	1	2	3	4	5
Ashamed	1	2	3	4	5
Inspired	1	2	3	4	5
Nervous	1	2	3	4	5
Determined	1	2	3	4	5
Attentive	1	2	3	4	5
Jittery	1	2	3	4	5
Active	1	2	3	4	5
Afraid	1	2	3	4	5

6. Listed below are a number of events that sometimes bring about change in the lives of those who experience them and which necessitate social readjustment. Please check those events in either column that you have experienced since turning 18 years of age.

	Not Applicable	Have Experienced		Not Applicable	Have Experienced
Marriage	0	1	Sexual difficulties	0	1
Major change in financial status (a lot better off or a lot worse off)	0	1	Trouble with employer (in danger of losing job, being suspended, demoted, etc.)	0	1
Death of spouse	0	1	Trouble with in-laws	0	1
Major change in sleeping habits (much more or much less sleep)	0	1	Foreclosure on mortgage or loan	0	1
Major change in eating habits (much more or much less food intake)	0	1	Minor law violations (traffic tickets, disturbing the peace, etc.)	0	1
Borrowing more than $10,000 (buying home, business, etc.)	0	1	Borrowing less than $10,000 (buying car, TV, getting school loan, etc.)	0	1
Male: Wife/girlfriend's pregnancy	0	1	Major personal illness or injury	0	1
Female: Pregnancy	0	1	Female: Having Abortion	0	1
Death of close friend	0	1	Being fired from job	0	1
Outstanding personal achievement	0	1	Male: Wife/girlfriend having abortion	0	1
Detention in jail or comparable institution	0	1	Marital separation from mate (due to conflict)	0	1

Question 6 Continued	Not Applicable	Have Experienced		Not Applicable	Have Experienced
New job	0	1	Divorce	0	1
Marital reconciliation with mate	0	1	Engagement	0	1
Married Male: Change in wife's work outside the home (beginning work, ceasing work, changing to a new job, etc.)	0	1	Changed work situation (different work responsibility, major change in working conditions, working hours, etc.)	0	1
Married Female: Change in husband's work (loss of job, beginning new job, retirement, etc.)	0	1	Beginning a new school experience at a higher academic level (college, graduate school, professional school, etc.)	0	1
Major change in usual type and/or amount of recreation	0	1	Reconciliation with boyfriend/girlfriend	0	1
Breaking up with boyfriend/girlfriend	0	1	Leaving home for the first time	0	1
Serious injury or illness of close friend	0	1	Separation from spouse (due to work, travel, etc.)	0	1
Beginning a relationship	0	1	Retirement from work	0	1
Major change in living conditions of family (building new home, remodeling, deterioration of home, neighborhood, etc.)	0	1	Financial problems concerning school (in danger of not having sufficient money to continue)	0	1

Question 6 Continued	Not Applicable	Have Experienced		Not Applicable	Have Experienced
Major change in social activities, e.g. parties, movies, visiting (increased or decreased participation)	0	1	Changing to a new school at same academic level (undergraduate, graduate, etc.)	0	1
Ending of formal schooling	0	1	Failing an important exam	0	1
Academic probation	0	1	Changing a major	0	1
Failing a course	0	1	Joining a fraternity/sorority	0	1
Dropping a course	0	1	Change of residence	0	1
Major change in closeness of family members (increased or decreased closeness)	0	1	Major change in church activities (increased or decreased attendance)	0	1
Gaining a new family member (through birth, adoption, family member moving in, etc.)	0	1	Major change in number of arguments with spouse (a lot more or a lot less arguments)	0	1
Son or daughter leaving home (due to marriage, college, etc.)	0	1	Being dismissed from dormitory or other residence	0	1
Death of close family member:			Serious illness or injury of close family member:		
mother	0	1	father	0	1
father	0	1	mother	0	1
brother	0	1	sister	0	1

Question 6 Continued	Not Applicable	Have Experienced		Not Applicable	Have Experienced
sister	0	1	brother	0	1
grandmother	0	1	grandfather	0	1
grandfather	0	1	grandmother	0	1
other (specify)	0	1	spouse	0	1
			other (specify)	0	1

7. Please answer the following open-ended questions as complete as possible. Please print clearly. If you run out of space, please feel free to write on the back. If these questions do not apply to you, please write Not Applicable or N/A below and move to the next page.

   A. Briefly explain how you came to provide care for a family member or close friend?

   B. Before today, did you identify yourself as a caregiver? Why or why not?

   C. Is/Are there thing(s) (extracurricular activities, employment, aspirations, etc.) that you have had to alter or give up since obtaining your role as a caregiver? If yes, please list below. If no, please leave blank.

   D. What are some of the good things (increased quality time, time management skills, etc.) you have experienced as a caregiver? If yes, please list below. If no, please leave blank.

Please provide us with some basic information about yourself.

1. How old are you? _____ 2. What is your major? _____

3. How long have you been providing care?

- ☐ Less than 6 months
- ☐ 6 to 11months
- ☐ 1 to 3 years
- ☐ 3 to 5 years
- ☐ More than 5 years
- ☐ Do not know
- ☐ Choose not to answer
- ☐ Not applicable

4. Are you currently employed?

- ☐ Full time (35 hrs/wk or more)
- ☐ Part time (less than 35 hrs/wk)
- ☐ Leave of absence
- ☐ Retired
- ☐ Not employed

5. What is your typical work schedule?

- ☐ Mornings
- ☐ Nights
- ☐ Evenings
- ☐ Various shifts
- ☐ Days (8/9 am – 5 pm)
- ☐ Not applicable
- ☐ Weekends

6. Has your employment status changed as a result of caregiving duties?

- ☐ No change
- ☐ Changed jobs
- ☐ Family/medical leave
- ☐ Leave of absence
- ☐ Increased hours
- ☐ Decreased hours
- ☐ Early retirement
- ☐ Began working
- ☐ Quit job
- ☐ Laid off
- ☐ Other (specify): _____

7. Ethnicity

- ☐ White
- ☐ African American
- ☐ Latino
- ☐ Asian American
- ☐ Native American/Alaska Native
- ☐ Other (specify): _____

8. What is your current relationship status?

- ☐ Married
- ☐ Spouse/Partner
- ☐ Separated
- ☐ Divorced
- ☐ Living together
- ☐ Widowed
- ☐ Single

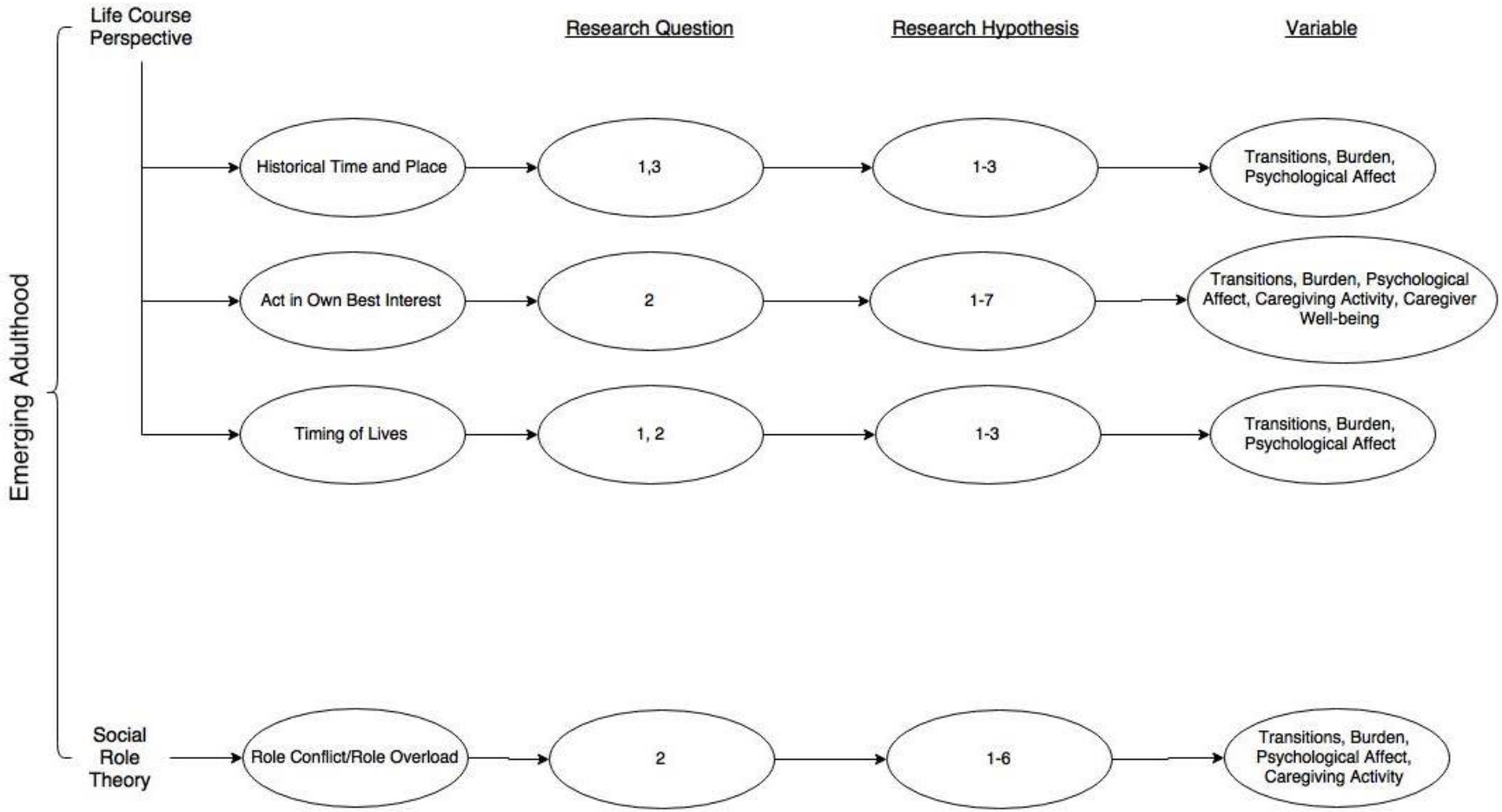
9. What is your sex?

- ☐ Male
- ☐ Female

Please use this space to add any further comments to the open ended questions that you may have. Be sure to indicate which question you are continuing to answer.

Appendix B

Concept Map


Emerging Adulthood
Life Course Perspective
Research Question
Research Hypothesis
Variable
Historical Time and Place
1,3
1-3
Transitions, Burden, Psychological Affect
Act in Own Best Interest
2
1-7
Transitions, Burden, Psychological Affect, Caregiving Activity, Caregiver Well-being
Timing of Lives
1, 2
1-3
Transitions, Burden, Psychological Affect
Social Role Theory
Role Conflict/Role Overload
2
1-6
Transitions, Burden, Psychological Affect, Caregiving Activity

Research Questions

1. What are the demographic characteristics of emerging adult caregivers?
2. Among emerging adult caregivers, are increased life events related to psychological affect and burden?
3. When compared with existing research on adult caregivers, do the results of this study show that emerging adult caregivers merit consideration as a classification of family caregivers distinct from other age groups?

Research Hypotheses

Since existing research does not provide a demographic profile of emerging adult caregivers, no specific hypotheses were established for Research Question 1.

1. Among emerging adult caregivers, reports of the quantity of transitions will be positively correlated with reports of caregiver burden.
2. Among emerging adult caregivers, reports of the quantity of transitions will be positively correlated with reports of negative psychological affect.
3. Among emerging adult caregivers, reports of the quantity of transitions will be negatively correlated with reports of positive psychological affect.
4. Among emerging adult caregivers, reports of caregiving activity will be positively correlated with reports of caregiver burden.
5. Among emerging adult caregivers, reports of caregiving activity will be positively correlated with reports of negative psychological affect.
6. Among emerging adult caregivers, reports of caregiving activity will be negatively correlated with reports of the positive psychological affect.

7. Among emerging adult caregivers, reports of caregiving activity will be negatively correlated with reports of caregiver well-being.

No hypotheses were established for Research Question 3 since this will involve reporting statistics in studies of older caregivers on the variables and demographics to identify areas where potential differences may be present.

Appendix C

Oklahoma State University IRB Approval Letter

Oklahoma State University Institutional Review Board

Date:	Tuesday, February 03, 2015
IRB Application No	HE152
Proposal Title:	Exploring Emerging Adulthood Caregivers: Does this Understudied Population Vary from Middle and Late Adulthood Caregivers?
Reviewed and Processed as:	Exempt

Status Recommended by Reviewer(s): Approved Protocol Expires: 2/2/2018

Principal Investigator(s):

Kristopher Struckmeyer
233 HS
Stillwater, OK 74078

Whitney Bailey
233 HSCI
Stillwater, OK 74078

The IRB application referenced above has been approved. It is the judgment of the reviewers that the rights and welfare of individuals who may be asked to participate in this study will be respected, and that the research will be conducted in a manner consistent with the IRB requirements as outlined in section 45 CFR 46.

The final versions of any printed recruitment, consent and assent documents bearing the IRB approval stamp are attached to this letter. These are the versions that must be used during the study.

As Principal Investigator, it is your responsibility to do the following:

1.Conduct this study exactly as it has been approved. Any modifications to the research protocol must be submitted with the appropriate signatures for IRB approval. Protocol modifications requiring approval may include changes to the title, PI advisor, funding status or sponsor, subject population composition or size, recruitment, inclusion/exclusion criteria, research site, research procedures and consent/assent process or forms
2.Submit a request for continuation if the study extends beyond the approval period. This continuation must receive IRB review and approval before the research can continue.
3.Report any adverse events to the IRB Chair promptly. Adverse events are those which are unanticipated and impact the subjects during the course of the research; and
4.Notify the IRB office in writing when your research project is complete.

Please note that approved protocols are subject to monitoring by the IRB and that the IRB office has the authority to inspect research records associated with this protocol at any time. If you have questions about the IRB procedures or need any assistance from the Board, please contact Dawnett Watkins 219 Cordell North (phone: 405-744-5700, dawnett.watkins@okstate.edu).

Sincerely,

Hugh Crethar, Chair
Institutional Review Board

VITA

Kristopher Mason Struckmeyer

Candidate for the Degree of

Master of Science

Thesis: EMERGING ADULTHOOD CAREGIVERS: EXAMINING THE UNIQUE EXPERIENCES IN THIS UNDERSTUDIED POPULATION

Major Field: Human Development and Family Science, Gerontology

Biographical:

Education: Completed the requirements for the Master of Science in Human Development and Family Science with a specialization in Gerontology at Oklahoma State University, Stillwater, Oklahoma in July 2015. Completed the requirements for the Bachelor of Arts in Psychology at Arkansas Tech University, Russellville, Arkansas in 2013.

Experience: Employed as Research Assistant, Oklahoma State University Department of Human Development and Family Science, 2013-present; Activities Coordinator, Red Bud Assisted Living, Perkins, Oklahoma, 2014-2015; Teaching Assistant, Oklahoma State University Department of Human Development and Family Science, 2013-2015;

Professional Memberships: Gerontological Society of America, National Society for Collegiate Scholars, Psi Chi International Honor Society in Psychology.